

IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by helen - 21 Oct 2008 13:06

Dear Doc Sarah, or anyone with some feedback please

I have total spine arachnoiditis (10 years)and my whole body is becoming very stiff and crunchy. Now its reached my neck and head I'm feeling petrified. I'm finding it hard to cope with symptoms and would really appreciate response from fellow sufferers - I feel very alone.

Thanks Helen

=====

Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by ann - 15 Nov 2008 18:10

hi helen,

i hope that you will accept our apologise pleasein not answering you sooner

kim has not been able to read at allbecause of her eyes (itis's) thingy and believe me reading is her life.... and is quite upset about the fact that it has taken so long this time to ease up a bit

we know that when you feel that no one is listening..... that you can feel so alone

as we have all felt at sometime ..if you haven't felt like that then you are very lucky

I know that the doctor is busy at the moment as has said that she will be on the board as soon as she can... and i have had a flu bug that long i cannot remember being with out it... i do hope that this helps a bit for now...but please know that you are aways in our thoughts and prayers

ann

=====

Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by helen - 30 Nov 2008 18:05

Dear Ann

Thanks for your message. I am finding things very hard to cope with - everyday my body is going into uncontrollable spasms, pulling, wrenching and spearing my body. I feel totally out of control and I don't think I can take much more. My GP cannot believe that all my symptoms are caused by the arachnoiditis, she doesn't think it can travel from the base of your spine up to your neck and face and affect arms, chest wall etc. I know she's wrong because she can't feel what I feel and its so frustrating and demoralising. She has referred me to a Neurologist in January, but I don't have any confidence in the medical profession any more.....!

Thanks for your support - sufferers need this lifeline. Helen

=====

Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by kev - 01 Dec 2008 00:07

I get so annoyed with the GP(s) at my surgery too as not only do all of them know absolutely zero about AA, they make no effort to even find out the smallest detail about it so every time i visit it's simply a case of "Ok so what do you want? More tablets or back to the Ortho?". And the Orthopaedic surgeon in question claims to know nothing either!

I have an MRI due next month after badgering the Ortho to investigate to see if the AA has spread or if i have a new pain source further up my back where i am getting a lot of new pain and spasm. also get the Chest pain Helen.

It's incredible so many people suffer so severely and there is next to no research going on.

=====

Re:IS ANYONE EXPERIENCING THE SAME AS ME ?

Posted by kev - 12 Dec 2008 02:01

Update to my situation. I had my MRI and they said there was no progression but that they found nerve compression outside the spinal canal. I asked if anything could be done and they said the nerve was enmeshed with masses of scar tissue and any attempt to free it would only damage it further.

This is all in the lumbar area but i am now getting lots of pain in the thoracic/cervical area due to the stretching of tissues/muscles in the lumbar area and the poor posture i have to endure. I now feel totally deflated, gutted as there appears to be no hope whatsoever for me on the horizon, only more pain and suffering and more disability. I have a daughter of 9 and a son of 4 who i adore but can barely play with.

However, i know were it not for them i would not be here now. I still often wonder what the point of keeping on living a hellish existence is.

Sorry to be so glum.

=====